**Final Evaluation Project Summary and Recommendations**
**September 2005**

## *Introduction:*

In 1999, CDC issued a recommendation that all states and territories conduct case surveillance of HIV in addition to the current AIDS surveillance. These guidelines were developed in response to the impact of advances in anti-retroviral therapy on the progression of HIV to AIDS, the implementation of HIV treatment guidelines, and the increased need for epi data on people at all stages of the disease.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, enacted in 1990 and reauthorized and amended in 1996 and 2000, provide funding for HIV care and support services. The CARE Act relies on annual appropriations from Congress and is comprised of four major program titles (Title I-eligible Eligible Metropolitan Areas (EMAs) disproportionately affected by HIV/AIDS, Title II-US states and territories, Title III-nonprofit entities, and Title IV-family-centered care for infants, children, youth, and women) and several other components. Formulas using data from AIDS case reporting system are used to allocate over 70 percent of RWCA funds through Title I and II. There have been concerns that such allocations are not equitable because the epidemic is not adequately reflected by AIDS cases alone, and that areas with emerging HIV epidemics are under-funded because all cases of HIV disease are not included. A related concern with basing allocations on AIDS cases is that jurisdictions are not compensated for providing early access to care and treatment. There is a widely held perception that incorporating HIV data in the formula would increase equity of RWCA allocation.

Prompted by these concerns, Congress specified in the 2000 reauthorization of the CARE Act that reported cases of HIV disease should be incorporated into RWCA Title I and II formulas as early as FY2005 – provided the Secretary of Health and Human Services determines that such data are available from all eligible areas and that they are "sufficiently accurate and reliable".

In response to this congressional mandate, HRSA and the CDC commissioned the Institute of Medicine (IOM) to address these concerns. In order to provide IOM with sufficient data, CDC will provide them with results of this evaluation project, to aid in making the determination on whether HIV cases could be used as part of the formula.

The Evaluation of the Performance of Integrated HIV/AIDS Surveillance Systems Project had participation of ten HIV/AID reporting areas: Michigan, Texas/Houston, Louisiana, New York City, New York State, New Jersey, Florida, Illinois/Chicago, Maryland, and Washington State/Seattle. These 10 areas include 8 areas that report HIV by name, 2 areas that use code to report HIV and 1 name-to-code area. Evaluation was done on 6 elements of the surveillance systems, which are detailed below. The project was expected to be completed by early 2003 in order for IOM to complete their review by September 2003. Due to the delayed implementation of an updated national HIV/AIDS reporting system (eHARS), evaluation of all elements were not complete by this time and were unable to be included in IOM's report. The current software used to support HIV/AIDS registries is HARS.

This document contains an abbreviated summary of this project. A more detailed description is available by contacting the evaluation project coordinator, Elizabeth Hamilton, at hamiltone2@michigan.gov.

# I. COMPLETENESS

a. **Standard**: HIV/AIDS surveillance systems should use reporting methods that provide case reporting that is at least 85% complete

b. **Results**
   i. National results
      1. 2 of the 8 programs met the standard of 85% complete case reporting
   ii. MI results
      1. No interactions
      2. Completeness of laboratory reporting estimated at 46%
         a. This project was conducted prior to implementation of legally mandated laboratory reporting in Michigan.
      3. Completeness of case reporting estimated at 81.5%
         a. Interpretation: By 6 months after initial diagnosis, our surveillance system captured 81.5% of expected diagnoses.
         b. Incompleteness is ~20%
      4. Current completeness estimate used for Prev. Estimate:
         a. Based on laboratory evaluation done in 2001
   iii. Current estimate used: 20%

c. **Recommendation:** No change in calculations for prevalence estimate, but re-evaluate completeness in 2006, after one year of complete laboratory reporting to adjust for increase in reporting. Hopefully phase out the 20% under-reporting estimate.

# II. TIMELINESS

a. **Standards**: 66% of cases must be reported within 6 months of diagnosis
b. **Results**:
   i. National Results
      1. 88% of states with HIV reporting at the time (27) had HIV cases reported within 6 months of diagnosis
      2. 78% of states had AIDS cases reported within 6 months of diagnosis
   ii. MI results
      1. Late 2001 (during Eval project)
         a. MI had 74% of HIV cases reported within 6 months of diagnosis
         b. MI had 68% of AIDS cases reported within 6 months of diagnosis
      2. Early 2005 (in preparation for implementing PA514)
         a. HIV, not AIDS
            i. About 72 % of HIV, not AIDS cases diagnosed in 2002 and 2003 were reported within 6 months of diagnosis
            ii. About 25% of HIV cases diagnosed in 2002 and 2003 were reported > 11 months or more after diagnosis.
         b. AIDS
            i. About 76 % of HIV cases diagnosed in 2002 and 2003 were reported within 6 months of diagnosis
            ii. About 21% of HIV cases diagnosed in 2002 and 2003 were reported > 11 months or more after diagnosis.
c. **Recommendation**: Measure time from diagnosis to entry into HARS at the end of each year (during cleaning), and track the expected improvements from lab reporting

## III. CASES OF PUBLIC HEALTH IMPORTANCE (CoPHI)

a. **Standard**: no national standard
b. **CoPHI definition**: A CoPHI case is one that is reported with a risk that requires immediate follow up, such as occupational exposure, pediatric sexual exposure, or suspected exposure through blood products.
c. **Results**:
    i. Of the 12 CoPHI cases reported during that time period, two were confirmed to be CoPHI (both were pediatric sexual assault cases: one occurred in Africa the other occurred in Mississippi and was already reported by Mississippi)
**d. Recommendation**: Although most NIRs do not lead to a confirmed CoPHI risk, continue to notify CoPHI Coordinator of all priority cases and follow the suggested follow-up procedure in the MDCH policy and procedure manual.

## IV. ASCERTAINMENT OF TRANSMISSION RISK (ATR)

a. **Standard:** 85% of cases with complete risk within a year of report (epi follow up completed)
b. **Results:**
    i. National
        1. HIV, not AIDS: 73%
        2. AIDS: 70%
        3. Overall: 72%
    ii. MI did not meet the standard
        1. HIV, not AIDS: 69%
        2. AIDS: 66%
        3. Overall: 68%
c. **Recommendation:** Expect this to remain low with the start of lab reporting. Be diligent about risk (when time allows) and continue to generate the No Identified Risk (NIR) lists twice a year, making note of those NIRs that are still remaining from the previous list. Continue to emphasize to reporting sites the need to document mode of transmission

# V. MATCHING TO OTHER DATABASES OF IMPORTANCE

a. **Standard**: No national standard; **Goal**: Measure the accuracy with which HIV/AIDS surveillance systems can identify proper match & non-match rates to other databases.

b. **Procedure**:
   i. Match to Syphilis database
   ii. Match to Vital Records (death data)
      1. Validate all matches where new vital status was gained (visually compare each match)
   iii. Match to Cancer database

c. **Results**:
   i. Syphilis match
      1. 1 match found from 21, 925 HARS and 45 Syphilis records
   ii. Vital records match
      1. 6,608 Matches found from 19,685 HARS and 1,414,217 Death records
      2. Info gained:
         a. New cases: 3
         b. Updated vital status and cause of death: 705
   iii. Cancer match
      1. 1,866 Matches found from 18,676 HARS and 855,098 Cancer records
      2. Info gained:
         a. New cases: 8
         b. New Cancer dx: 596
         c. Update from HIV to AIDS: 29

d. **Recommendation**: Before doing anymore matches of this type, purchase matching software OR if the match is done with 'made from scratch' soft ware, validate all matches of concern (i.e., for death match, validate all cases with new vital status and for cancer match, validate any updates from HIV to AIDS)

# VI. ACCURACY AND RELIABILITY

## A. INTER-STATE DUPLICATION (IDEP OR RIDR)

i. **Standard**: No more then 5% inter-state (between state) duplication

ii. **Procedure**:

1. CDC matched all cases in their database on a combined variable of alphanumeric soundex code, date of birth, sex and asked states to determine if these potential matches were the same person AND which state had the earlier diagnosis of AIDS (or HIV if both cases were HIV, not AIDS) on cases reported through Dec 2001

**iii. Results**

1. Done in two rounds (IDEP I and IDEP II) and uploaded into MI HARS Oct 2004
    a. Lost 367 cumulative AIDS cases (of these 144 are persons living with AIDS)
2. Lost 337 cumulative HIV/not AIDS cases (of these 268 are persons living with HIV/not AIDS).
3. See attached graph

iv. **Recommendation**: Continue to participate in RIDR (Routine Inter-state Duplication Review), uploading to HARS at next available quarterly cleaning. Include a note in the cover memo that this upload will be routine and to contact surveillance staff for questions about apparent discrepant data.

## B. INTRA-STATE DUPLICATION

i. **Standard**: No more then 5% intra-state duplication

1. Proper match rate (PMR) $\geq$ 90% and $\leq$ 5% duplicate cases reported
2. Proper non-match rate (PNR) $\geq 1-(0.1/C)$ and $\leq$ 5% incorrectly matched cases reported, where $C$ is the total number of unique STATENOs in its Accuracy, Completeness, and Code Performance (ACCP) database.

ii. **Procedure**:

1. Validate 800 record pairs entered ACCP on four criteria:
    a. Proper match
    b. False match
    c. False non-match
    d. Proper non-match

iii. **Results**:

1. National
    a. No states are under reporting their cases (all met the standard)
2. MI
    a. Due to missing documents, MI validated 739 out of 800 record pairs entered ACCP on four criteria:
        i. Proper match: 286
        ii. False match: 10 (most were data entry errors)
        iii. False non-match: 15 (part entry error, part true errors which were already corrected in HARS
        iv. Proper non-match: 428
    b. MI met both standards:
        i. PMR: 95.2%
        ii. PNR: 99.99%

iv. **Recommendation**: Continue checking HARS before entering all new cases and running the duplicate checking program as part of the quarterly cleaning.

## *Conclusion:*

Below are summaries of findings for the IOM report to Congress (*information was gathered from IOM report, HHS website, NASTAD 9/6/05 Reauthorization Watch, vol 3 email & conversation with Kate Glynn (CDC))*:

-IOM released *Measuring What Matters: Allocation, Planning, and Quality Assessment for the Ryan White Care Act* on November 7, 2003.

**Overall Conclusion:**

Reporting of HIV cases is not yet complete and accurate enough nationwide to allow these numbers to be used in CARE Act allocation formulas, and that HRSA should continue using estimated living AIDS cases in formula awards for at least the next four years in order to give states more time to improve HIV reporting or develop alternative strategies to case reporting.

Specific ideas to be taken from the IOM document:

**1. Eliminate Current Provisions That Entitle Cities To Be "Held Harmless" In Funding Reductions.**
Today, because of the way the existing formulae count the number of AIDS cases (by including cases spanning the last 10 years), metropolitan areas with newer epidemics receive disproportionately less than those with more longstanding problems. In order to more accurately reflect the current status of the epidemic, we must eliminate provisions that entitle cities to be "held harmless" in funding reductions.

**2. CDC should figure out how to incorporate Code-to-Name States' data.**

Since the 2000 reauthorization, all 56 states, territories, and local health departments have implemented some type of HIV reporting. Currently 44 use confidential name-based reporting, while the remaining 13 use code-based or name-to-code methods. CDC has not accepted HIV case report data from these jurisdictions, determining that these systems do not meet national performance and evaluation standards. The vast majority of these jurisdictions are currently taking steps, through legislative or regulatory action to switch to name-based reporting

July 2005, CDC Director, Julie Gerberding, officially recommended that all states and territories adopt confidential, name-based HIV surveillance systems.

**3. IOM suggested using estimated numbers of HIV in funding formula**

*This is prohibited by law (exact numbers must be used)

**Decisions since the IOM report was released:**

1. **In June 2004**, the Secretary of the Department of Health and Human Services (HHS) determined that the CDC lacked data on cases of HIV disease that were sufficiently accurate and reliable to be used to make formula grants under Title I and II of the CARE Act.
2. **Under current legislation***,* in 2007, the data that CDC will send to HRSA will be reported cases of HIV and AIDS reported between July through June of each 12 month cycle from July 1996 to June 2006. For all areas with name-based HIV reporting systems, the number of cases will be the number of HIV and AIDS cases reported to date. All reported cases of HIV that are reported to CDC will be used in the formula, regardless of how long a jurisdiction has been reporting HIV to CDC (some have started since 2001 and CDC does not consider this 'mature' enough to calculate 4 years of reporting delays that allow for reliable trend data). For areas with systems other than name-based reporting for HIV, the number of cases reported to HRSA for use in CARE Act calculations will only be the number of AIDS cases reported to CDC. Current legislation expires September 2005, but will be in effect until Congress reauthorizes it

**Trends in National and Michigan HARS after completion of IDEP (Uploaded late-2004)**